
Continence Clinic Project

Outcome Measurement for Victorian Continence Clinic Services



National Ageing Research Institute

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Participating teams:

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NARI staff:

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Executive Summary:

Background:

Incontinence is increasingly growing as one of the largest health issues confronting the Australian community. Incontinence affects people of all ages, both sexes, and people of every social and economic level. From an economic perspective, Australians spend over \$1 billion dollars each year on incontinence. A far greater cost is associated with the direct impact incontinence can have on people's self-esteem, dignity and level of independence.

The Victorian Department of Human Services (DHS) fund 17 Continence Clinic Services throughout the state. Continence Clinic Services provide "... professional advice, support and information to all on the promotion of continence and the management of incontinence" (DHS, 2001, p. 7).

In 2000/2001, a Continence Clinic program guidelines and performance indicators document (DHS 2001) was developed and published by a working party established by the Aged Care Branch of the Department of Human Services. This document was developed to:

- Assist service providers in setting minimum service requirements; and
- Enable purchasers to determine what constitutes a quality service.
- Help the public to understand the main components of the services they receive

This document was in the process of being reviewed by the Victorian Department of Human services and a DRAFT document was developed and provided to the National Ageing Research Institute in 2003 (unpublished 2003).

Project Aims:

The DHS commissioned the National Ageing Research Institute (NARI) to *seek feedback from experts in the field on the DRAFT best practice guideline document and to finalise this report given the feedback provided*. The final version of the Best Practice guideline document is provided as a separate report.

In the early stages of the NARI/ DHS project implementation, a significant body of work on Outcome Measures (DRAFT form) was identified (project undertaken by LaTrobe University Faculty of Health Sciences for the Commonwealth Department of Health and Ageing, November 2003). Following consultation with representatives from both LaTrobe University and the Commonwealth Department of Health and Ageing, it was agreed by the NARI/ DHS project steering committee that the 'best practice guideline project' would also include a service field test of some of the measures identified within the LaTrobe university DRAFT report. This was therefore incorporated into the methodology and a second project aim was developed - *To field-test outcome measures as identified within the Continence Outcome Measurement Suite Project DRAFT report to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services*.

Project Methodology and Results:

A workshop was held with experts from the field and the outcome measures as identified within the DRAFT Continence Outcomes Measurement Suite project report (LaTrobe 2003) were reviewed. Three tools were recommended for field-testing within Victorian Continence Clinic services. These tools were the Wexner/ Cleveland Clinic Faecal Incontinence Score; the Urogenital Distress Inventory – Short form and the Kings Health Questionnaire. A standard bladder diary incorporating recommendations from the 2nd ICS/ WHO Consultation on Incontinence was recommended for trial, as too the Modified Care-giver Strain Index – a tool not reviewed in the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003).

Fourteen services were recruited and were involved in an information session where the tools were presented and the demands of the research project considered. These 14 services then field-tested the tools on a consecutive series of clients for an approximate one-month period. Feedback was provided on the applicability and practicability of these tools via focus groups with Continence Service staff and via data collection sheets completed by practitioners post use of the assessment with each client.

An outcome measurement survey was also developed and sent to all Victorian DHS funded Continence Clinic Services. The survey aimed to identify current outcome measurement use, and staff opinion about relevant outcome measure domains and tools, to help inform the development of an outcome measurement framework.

There was considerable variability in the use of outcome measurement tools across services. No outcome measures were being consistently used across services or across client groups. Outcome measurement was seen by all services as a minimum expectation in today's evidence based health service environment and as required in order to better judge the efficiency and effectiveness of Continence Clinic Services and client outcomes.

Outcome measures were identified as needing to be simple to use and time efficient to administer if they are to be accepted by practitioners. Traits such as the tool's ability to be translated into different languages and its ability to be administered in different ways were also valued. Most services identified benefits in having commonality in core outcome measurement across the state. Having one or a few tools to use with all clients across all services and then having a suite of tools to draw upon to meet individual service or client needs was a concept largely valued.

All services identified benefits and weaknesses for all of the outcome measures trialed in this project and all services identified that no tool or selection of tools could replace existing assessment practice. Whilst assessment practice was not considered as part of this project, this finding has important implications as, if recommended, any of the outcome measures trialed will need to be implemented in addition to existing service demands. Concern was also expressed by most services about how data collected by the outcome measures would be interpreted and used, and most services identified a need for a longer trial and evaluation period to further determine any of the tools measurement merits.

In the future, five regional and rural services identified that they would consider using the Wexner/ Cleveland Clinic Faecal Incontinence Score, Kings Health Questionnaire and the Modified Caregiver strain index on admission and discharge for all clients presenting to a Continence Clinic service. Six additional services identified that the Wexner/ Cleveland Clinic Faecal Incontinence Score and the Urogenital Distress Inventory short form could be used by all clients presenting with faecal and urinary incontinence respectively. Most services identified that the Kings Health Questionnaire should be used for a target population presenting with urinary incontinence (mostly described as younger in age and cognitively able) and for research purposes.

Project critique:

The results described above need to be interpreted in the context of limitations including the following:

- The project aimed only to field test tools as identified within the Continence Outcomes Measurement Suite project DRAFT report – with the aim of exploring issues related to tool applicability and practicability. The tool's ability to detect change related to Continence Clinic health service intervention can therefore not be reported on in this project report.
- This project did not consider tools or outcome measurement domains outside of those identified within the Continence Outcomes measurement suite project DRAFT report (LaTrobe 2003). As

such, domains including client goal attainment and satisfaction (measurement domains identified within the outcome measurement survey as important by many services) were not considered.

- A context was established at the beginning of the project for the development of a suite of core outcome measures to use across all client groups and all services, and then recommended tools that could be drawn upon to meet local needs and interests. A 'one size fits all approach' could be considered a limitation to this project.

Recommendations:

There were two aims for this project. The recommendations detailed in this report only relate to Project Aim Two. Project Aim One was to finalise the best practice guideline document post feedback from an expert steering committee – the outcome of this aim is provided in a separate report. Project Aim two was to field test outcome measures as identified within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003) to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services. The recommendations identified as a result of the project methodology adopted to meet Project Aim Two are as follows:

- Recommend the development of a minimum set of core outcome measures to use across all Continence Clinic services and all client groups in the context of a broader suite of tools to draw upon to meet local needs and interests.
- Where there is a desire to use a common measurement approach for all clients presenting to Continence Clinic Services in Victoria the following tools should be considered as part of a more formal trial given their general field acceptance from a practicability and usability perspective: The Wexner/ Cleveland Clinic Faecal Incontinence Score and the Urogenital Distress Inventory – Short Form. The King's Health Questionnaire was considered beneficial for research purposes.

Project activity recommended as a result of this project:

- This project considered evaluation related to tool acceptability and usability. There is a need for a formal trial of any recommended measures for a sufficient period in order to profile clients who access continence services, and to identify the usefulness of the recommended measures in identifying change in response to intervention. Throughout this time, there is a need to monitor the effect of any additional demands placed on services – for example implementation of the Service Co-Ordination Tool Templates on issues regarding measure acceptability and practicability. All tools field-tested were identified as being inappropriate for administration with some clients – for example, clients accessing a service for a repeat prescription of continence aides or clients presenting with impaired cognition. It is recommended that a profile of these clients be collected to determine if other measures are more appropriate to identify change associated with intervention for these client groups.
- This project only considered outcome measures recommended within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003). Additional measurement domains were identified by practitioners as needing to be incorporated into an outcome measurement framework but were not included in this project activity. Examples of such domains include - measures or a process for documenting and evaluating client goals, measures addressing client and caregiver satisfaction and measures addressing constipation and quality of life related to faecal incontinence. These measurement domains would benefit from further exploration.
- Reducing continence related caregiver strain and demand is commonly reported as a goal requiring continence service intervention. Most services identified the need for further research in this area.

- That the outcome measurement process remain a dynamic one with opportunities provided for continual review – including consideration of recommendations and discussion from the 3rd International Consultation on Incontinence in Monaco July 2004. Further investigation of work completed by the Continence Physicians group on outcome measurement (1998) is recommended.

Project Activities:

The following project activities were undertaken: (Appendix One: Project Proposal)

Phase One: Project Development and Preparation

- Established Project Steering Committee and Working Committee including DHS project staff, field representatives across a number of disciplines, and regional and metropolitan representatives.
- Developed and disseminated a survey (Appendix Two: Outcome Measurement survey) to determine current use of outcome measures across DHS funded Victorian Continence Clinic services. Seventeen surveys posted. Eleven returned (65% response rate).
- Disseminated the existing DRAFT best practice guideline document (not published 2003) for steering committee review and comment. Disseminated the existing Best Practice guideline document (DHS 2001).

Phase Two: Field testing of Outcome Measures

- NARI facilitated a working group with steering committee members to review measures as identified within the Continence Outcomes Measurement Suite DRAFT report (LaTrobe University, 2003). Steering committee identified four measures for field-testing (Appendix Three: Measures for field-testing) and expressed interest in field testing the Modified Caregiver strain index (Thornton et al 2003).
- Recruited services to field-test the Outcome Measures as identified by the project steering committee. Fourteen services recruited representing metropolitan, rural and regional Victoria.
- Information session for recruited Continence Clinic services to present Outcome Measures and consider project requirements. Eight information sessions conducted averaging two hours in length. Information sessions included: Background to project; Presentation of tools to be trialed; Implementation and evaluation issues.
- Outcome Measures field-tested in fourteen Continence Clinic services. Field-testing occurred for 4-6 weeks. Practitioners were encouraged to use the outcome measures with a consecutive number of new clients being admitted to the service during the established time period. The Wexner/ Cleveland Clinic Faecal Incontinence Score was recommended for use with all consecutively admitted clients presenting with faecal incontinence symptoms. The UDI and the Kings Health questionnaire was recommended for use with all consecutively admitted clients presenting with urinary incontinence symptoms. The Modified Caregiver strain index was recommended for use with all clients who had a primary carer attend the assessment visit. The bladder diary was recommended for use with all clients presenting with urinary incontinence symptoms. A de-identified client-tracking sheet was provided to each service. Some measures were not considered appropriate by practitioners for administration to some clients. Services were asked to document reasons why a client was not administered a particular tool.

Phase Three: Outcome Measurement evaluation

- Received and analysed responses from Outcome Measures survey – presented to steering committee for their expert opinion and review.
- Focus groups (Appendix Four: Focus group questions) with recruited Continence Clinic services regarding the acceptability of the Outcome measures used. Eleven services were involved in the focus groups, one additional service provided written feedback to focus group questions. Presented findings to the steering committee for their expert opinion and review.
- Report provided to the steering committee on the Outcome Measures component of the NARI/ DHS project.

Phase Four: Finalisation of Best Practice guideline document

- Steering committee provided feedback about the existing Best Practice guideline document.
- Feedback incorporated to assimilate a FINAL Best Practice guideline document.

Summary of Timelines:

Key Tasks	Time Lines
Established Steering Committee	November 2003
Developed, Disseminated and assimilated results from Outcome Measures survey	December 2003 – February 2004
Steering Committee meeting reviewed revised project proposal, discussed limitations, reviewed terms of reference for working group, discussed preliminary results of outcome measures survey, DHS disseminated DRAFT best practice guidelines document and existing best practice guidelines document.	February 2004
Compiled a manual of outcome measures as recommended in the DRAFT Commonwealth Department of Health and Ageing report (LaTrobe University 2003)	February 2004
Workshop with steering committee - reviewed recommended measures/ selected measures for field testing/ considered field testing protocol and carer measures	March 2004
Recruited Continence Clinic services	March 2004
Information sessions for Continence Clinic services	March 2004
Continence Services Field tested measures	April 2004
Continence service Focus Groups	May 2004
Assimilated results from focus groups. Presented results to steering committee. Assimilated feedback. Provided report on Outcome measures project.	June 2004
Assimilated feedback of DRAFT best practice guidelines document	June 2004
Steering committee reviewed reports	July 2004
Presentation of final report	July 2004

Results:

Outcome Measures Survey

An outcome measurement survey was developed by the National Ageing Research Institute and sent to seventeen DHS funded Continence Clinic services.

The survey was conducted for two reasons. Firstly to identify outcome measurement tools that were being used currently within all Victorian DHS funded Continence Clinic services and secondly to identify domains or specific measures considered necessary to be included in an outcome measurement framework. Practitioners were asked to consider outcome measurement in relation to measures/ domains recommended for use on a 'routine basis' and measures/ domains recommended for use on an 'as needed basis'.

'Routine basis' in the context of the survey, referred to measurement tools or domains recommended to be used for all clients presenting to the service on their admission and discharge to the Continence Clinic service. 'As needed basis' referred to measurement tools/ domains recommended for use on an 'as needed basis' to use on a selected subset of clients to address local needs and interests.

Eleven out of seventeen DHS funded Continence Clinic services returned the questionnaire (65% Response Rate). Of these services, four were from Regional Victoria.

Measures currently used on either a 'routine' or 'as needed' basis

The first question asked services to list all of the Outcome Measures they were using on either a 'routine' or 'as needed' basis. (Table 1).

The results for this question need to be interpreted carefully as some Continence services included various *assessment* tools they were using on admission rather than specific outcome measures being used at two or more time points to measure change. For example, three services indicated that they used the Bladder and Bowel symptom questionnaire. This questionnaire was developed as an assessment tool by the Continence Physicians Group (1998). The questionnaire has various outcome measures within it – some validated and some not and the purpose when developing the questionnaire was for these outcome measures to be completed again on a client's discharge. The focus group results suggested that at least five of the recruited services were using the questionnaire, but as most services indicated the outcome measures within it were not being used at two time points, they did not include the questionnaire within their Outcome Measure survey results. It was not the purpose of this project to review assessment practices in Victorian Continence Clinic Services.

For thoroughness, a summary of all of the responses has been included in Table 1.

Specific tools or assessment domains being considered by services for use:

The second question asked services to list any outcome measures that were not currently being used, but which services were considering using or trialing in the future. Ten out of eleven services commented on this question. The results are provided in Table 2.

Table 2: Tools or assessment domains being considered for service use

(n=10)

Specific Measure:	Number of services
Bladder and Bowel symptom questionnaire	3
24 hour pad weight	2
Kings Health Questionnaire	2
Urogenital Distress Inventory - long form	1
Constipation scoring system	1
Faecal incontinence QoL scale (Rockwood)	1
Continence Scale	1
Functional Independence Measure	1
Domain	
Quality of Life (QoL)	4 (1 service reported the need for such a measure to be client administered)
Faecal incontinence QoL scale	1
Goal attainment	2
Client satisfaction	2
Functional assessment	1
Number of diagnosis	1

In relation to specific measures services were considering trialing, the 24 hour pad weight, the Kings Health questionnaire and the Bladder and Bowel Symptom questionnaire were the most commonly reported.

Quality of Life, goal attainment and client satisfaction were the most commonly reported domains services were investigating for outcome measurement purposes.

Domains considered important to include in a measurement framework:

The third question asked services to indicate whether they would consider measuring various domains on either a 'routine' basis or 'as needed basis' for clients. Whilst some domains were specified (Continence Clinics – Program Guidelines and Performance Indicators 2000, p14), services were encouraged to list any other domains as required. The domains provided included: patient symptom measures, practitioner measures, anatomical measures, patient function measures, carer measures, quality of life measures, client specific measures and socio-economic measures.

Services were also encouraged to list any specific outcome measures they considered were appropriate within these domains in the consideration of the development of a core set of outcome measures or a suite of tools for recommended use by Continence Clinic services.

The following results were obtained:

Additional comments regarding outcome measurement:

The fifth question asked services to provide any additional comments regarding the topic of outcome measurement. Seven of eleven services responded. The following provides a summary of the comments provided. The summary details comments provided about outcome measurement/assessment practice and key performance indicators.

Recommendations regarding outcome measurement were described as needing to be "meaningful" (1) and able to be used by all practitioners across the state (1). Uniformity in assessment was considered advantageous as long as it did not become too prescriptive (1). Whilst many domains were considered as important to measure for many clients, not all were seen as appropriate to include within an outcome measurement framework for all clients across all services for example, client goal attainment (1). The need for a tool to be clinically useful was valued (1) in addition to the tool's utility as an outcome measure (1). The need for measures to be simple to use and administer, without an excessive time requirement was considered necessary (1) particularly for services with limited resources (1).

Final data collection was identified as needing to be "integrated" and "relevant" to existing assessment practices and not simply a collation of pages of individual tools (1). The need to view the measures in a co-ordinated manner was valued as opposed to considering change in individual measures (1).

One service suggested the Continence Assessment Minimum Data 1998 was a useful starting point in considering outcome measurement for Continence Clinic services, but indicated it would need to be further refined requiring field consultation. Another valued the need for a simple quality of life tool.

Gathering demographic information on client's attending the service was valued (1) with examples of age; ethnicity and area in which the client was residing provided. This information was seen as beneficial for planning and funding purposes (1) and was seen as necessary for interpreting outcome measurement results. This service described limitations of the existing DHS Key Performance Indicators, indicating that additional information such as type of urinary incontinence; treatment and investigations required should also be captured to determine the personal requirements needed within a service.

Workshop with field representatives:

An expert steering committee that also acted as a working party was developed in the early phases of this project. This group comprised nursing practitioners, physiotherapists, medical staff and service co-ordinators from both regional and metropolitan Victoria.

As part of the methodology, the working group attended a workshop to review the outcome measures identified within the Continence Outcomes Measurement Suite Project – DRAFT report (LaTrobe 2003). Working party members were asked to review the tools with respect to how *applicable* the tools were for their client population and how *practicably* the tools could be incorporated into existing Continence Clinic services.

Concerning applicability, working party members considered factors including the relevance of the domains assessed in each tool; the appropriateness of the depth of information gained to meet service needs and the extent to which the tool would complement or duplicate existing assessment processes. In relation to the practicability issues, working party members considered factors including the perceived need for staff training in tool use and the ability to incorporate the new measurement demand given existing resources.

Urogenital Distress Inventory (UDI) – Short Form:

The UDI was seen as reasonably quick to administer and score, requiring no training to use (10). The tool was often described as “simple” but not comprehensive enough for all clients - for example, it did not assess nocturnal incontinence; incontinence related to poor mobility, passive incontinence and vaginal pain (7).

The tool would need to be used in addition to standard assessment practice (12). For example it missed a lot of the detail required for assessment purposes such as fluid intake and frequency (1). The tool was not seen as adequate to “drive intervention” (1). One service identified that it could be easily incorporated into standard assessment practice if it was to be adopted in the future.

Seven services perceived that most of their clients would be able to self administer the tool. Three services identified the need for a clinician to administer the tool due to differences in client interpretation of the questions - related to client variables such as insight and cognition. One service identified that the method of administration would need to be left to practitioner’s discretion. All services identified that it would not take a great deal of additional time or resources for this tool to be administered and scored by the clinician (12).

Questions about the bother attributed to incontinence symptoms were perceived by practitioners to be repetitive – sometimes confusing the client (9). Two services commented that because of the repetitive nature of the ‘bother’ questions, practitioners were tempted to inappropriately influence the result when they were administering the tool – sometimes skipping questions or assuming the client response. One service liked the consideration of bother in this tool (1).

One question in particular was difficult to understand. This question was ‘do you experience small amounts of urine leakage’. Clients and practitioners were unsure how this question should be answered if the client experienced large amounts of urine leakage or ‘flooding’ (7).

Three services felt more information was required regarding score interpretation.

Eight services would use the tool again for all clients presenting with urinary incontinence symptoms. Four services would not use the tool again because it lacked comprehensiveness and was seen as insensitive enough to detect change for most of their client population (4).

One service that would not use the tool again for outcome measurement purposes identified its potential value as a screening tool (1).

In comparison to the Kings Health Questionnaire, eight services would prefer to use the UDI on a day to day basis, as it is quick and easy to administer and score.

Kings Health Questionnaire:

The measure was identified as a “good screening tool” - “(it) covers most assessment bases”(6) and ‘helps to initiate conversation in areas that are often embarrassing for clients to talk about’ (1). It was also identified as being readily able to ‘screen’ where more in-depth assessment was warranted (6). One service valued the tool’s ability to describe the patient versus the clinician perspective of the problem. While this was always a service aim, it was sometimes not achieved in usual assessment practice (1).

The first page of the Kings Health Questionnaire was considered to have the most essential information required for assessment for all clients presenting with urinary incontinence symptoms (5).

Conflicting views were expressed about the benefit of incorporating information obtained in bladder diaries in to an outcome measurement framework. Obtaining discharge information was a difficulty reported by most services. Most services were receptive to using a similar bladder diary across services.

Outcome measurement domains not reviewed in this process:

Eight services identified the need for a tool that assessed and measured change related to constipation and six identified the need to measure quality of life related to faecal incontinence and not just urinary incontinence.

Five services felt a suite of tools needed to be developed for children as well as adults.

Five services identified that client goals or 'the client's primary reason for accessing the service' and whether this had been achieved, needed to be considered in any outcome measurement framework.

Three services identified there may be benefit in using some or all of the three quality of life questions as found in the bladder and bowel symptom questionnaire.

Two services identified the need for a carer measure that was more continence specific.

Recommendations:

There were two aims for this project. The recommendations detailed in this report only relate to Project Aim Two. Project Aim One was to finalise the best practice guideline document post feedback from an expert steering committee – the outcome of this aim is provided in a separate report. Project Aim Two was to field test outcome measures as identified within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003) to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services. The recommendations identified as a result of the project methodology adopted to meet Project Aim Two are as follows:

- Currently there is considerable diversity in the number and range of outcome measures used by Victorian Continence Clinic services. Although there are benefits to having diversity across Continence Clinic services, there are also benefits in having at least a small amount of common measurement. This project recommends the use of a common approach to outcome measurement across services. Use of common core outcome measurements can be used to share information between services, to use as a basis for ensuring best practice, and could have potential for use in multi-clinic research. Implementing core common outcome measures should not be considered prescriptive or limiting to the range of measures used by services. Services should still have the capacity to add additional measures to address local needs and interests.
- Where there is a desire to use a common measurement approach for all clients presenting to Continence Clinic services in Victoria the following tools should be considered as part of a more formal trial given their general field acceptance from a practicability and usability perspective: The Wexner/ Cleveland Clinic Faecal Incontinence Scale and the Urogenital Distress Inventory – Short Form.

The King's Health Questionnaire was considered beneficial for research purposes or for use with a target population mainly described as younger in age and cognitively alert.

Project activity recommended as a result of this project:

- This project only considered outcome measures recommended within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003). Additional measurement domains were identified by practitioners as needing to be incorporated into an outcome measurement framework but were not included in this project activity. Examples of such domains include - measures or a process for documenting and evaluating client goals, measures addressing client and caregiver satisfaction and measures addressing constipation and quality of life particularly related to faecal incontinence. These measurement domains would benefit from further exploration. In writing this report, NARI was aware of a concurrent project considering patient satisfaction in the context of incontinence being conducted by Associate Professor Graeme Hawthorne at Melbourne University.
- Reducing continence related caregiver strain and demand is commonly reported as a goal requiring continence service intervention. Most services identified the need for further research in this area.
- Recommend use of a bladder diary incorporating at a minimum factors including: fluid input (type, time, amount); fluid output (time, volume) and comments (e.g. activity participating in when leaked). Recommend bladder diaries be used at admission, discharge and at interim points throughout a person's episode of care and be used ideally for three consecutive days.

